Uncovering Counselling Skills as Buried Treasure

HIV/AIDS Counselling Workshop

Western Shore, Nova Scotia
25-27 October, 1991

Sponsored by

Nova Scotia Department of Health

Health and Welfare Canada

Santé et Bien-être social Canada

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"Each one of us has the inner strength to transform a dead end into a path, a wall into an opening.... To come into contact with this inner strength is to uncover our buried treasure."

—Nena M. Nera, from the Closing Remarks

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Introduction

by Theresa Marie Underhill
Director, Health Promotion
N.S. Department of Health
& Workshop Chairperson

From the start, the concept of bringing together a diverse group of people to plan and carry out an HIV/AIDS Counselling Workshop appeared both challenging and overwhelming. As the process got under way, the group dynamic surged with energy and enthusiasm, not all of it harmonious. Nonetheless, despite incredible demands, the participation was tremendous. There always existed a strong commitment to bring together the resources that could help deal with the frustrations, anxieties, and problems faced by the people who have HIV/AIDS and those who care for them.

The workshop was intended to be an initiative, not merely an event. What does this mean? We saw the workshop as the start of something more—something larger, more far-reaching, and more powerful than any of us could imagine. By bringing people together, learning with them, teaching them, and sharing their experiences and emotions, we hoped that strong linkages would develop. Then a functioning, effective HIV/AIDS counselling network for Nova Scotia could truly be started. On this hopeful foundation a strong and nurturing structure could be built.

I want to thank Health and Welfare Canada for having the foresight to support and encourage the development of HIV/AIDS counselling skills in all the provinces and territories. I also want to recognize the contribution made by the Nova Scotia Department of Health, which assisted in the funding of this initiative. Most of all, I want to thank the Advisory Committee members and all those who participated in this landmark workshop.

A Federal-Provincial Initiative

The World Health Organization's Global Program on AIDS has stressed the importance of responding to the AIDS pandemic on a psychosocial front. Physicians, educators, and caregivers must establish networks to help each other learn effective counselling tools.

To this end, Health and Welfare Canada, under its National AIDS Strategy, collaborated with the provinces and territories and provided funding for provincial and regional training workshops on counselling. This is a nationwide initiative, and workshops have already taken place in British Columbia, Alberta, Manitoba, Ontario, Quebec, New Brunswick, and Prince Edward Island.

The objectives of the initiative are:

- to enhance and expand the HIV/AIDS counselling capacity in each province;
- to facilitate the networking of people, groups, and agencies involved in providing counselling and psychosocial support in the HIV/AIDS context;
- to facilitate a common understanding and support among those involved in HIV/AIDS counselling;
- to identify current and potential roles of professionals, families, friends, and peer groups in counselling;
- to identify regional and provincial needs for training and support systems, and to motivate regional and community initiatives that will further respond to these needs;
- to identify counselling methodologies and content.

The Nova Scotia HIV/AIDS Counselling Workshop took place October 25-27, 1991, at the Oak Island Inn in the coastal town of Western Shore. Nearby is Oak Island itself, which has long been reputed to be the site of buried treasure; as early as 1795 the discovery of a shaft leading to an underground system of flooding tunnels initiated a series of treasure hunts that would continue over the following two centuries.

This colourful lore inspired the workshop theme: "Uncovering Counselling Skills as Buried Treasure." When we probe our experience we discover rich resources of empathy and compassion, as well as the personal fears that must be unmasked and overcome along the way to becoming more effective counsellors. As Dr. Stephen Woo remarked in his keynote address, "Sometimes what is buried can have a far more meaningful impact than what is obvious or laid out. It is important for each of us to look within ourselves to see what we can offer those affected by this epidemic."

Preparing the Ground

An Advisory Committee made up of 15 individuals representing the various groups involved in HIV/AIDS counselling in the province came together to plan the workshop (see Appendix 7 for a list of members). Of these, a core group was responsible for implementing the planning process on a day-to-day basis.

GUIDING PRINCIPLES

The Advisory Committee's guiding principles were as follows:

- The initiative is a process, not an event.
- The initiative is directed to people involved with providing care.
- The process recognizes the diversity of needs of persons involved in the disease, according to their role (the person infected, caregivers, family, friends, partners), circumstances (where they live, background, experience), and level of knowledge about HIV/AIDS.
- The process encourages the development and use of new resources and strategies.
- The initiative recognizes the unique and crucial role played by a variety of disciplines in the counselling process.
- Presenters will be both people with HIV/AIDS and people who are their support systems.
- Participants will be presented with new information and will be actively involved in discussing counselling issues.
- The initiative is the beginning of a process towards developing HIV/AIDS counselling skills throughout the province, in all regions and communities.

NEEDS ASSESSMENT

As part of the planning process, input was gathered from a number of focus groups across the province. A total of 52 individuals participated in sessions representing five geographic areas and two interest groups: the Valley AIDS Concern Group and the Nova Scotia Mi'kmaq Task Force on AIDS. Each session was one and a half to two hours in length and focussed on a list of 23 questions (see Appendix 2). This needs assessment identified gaps in the existing HIV/AIDS counselling services as well as themes and issues to include in the workshop agenda.

Generally, recommendations focussed on the need for more counselling services in rural areas, including training for professionals in existing clinics and the

establishment of AIDS clinics. Concern was also expressed that, while health professionals are more knowledgeable about HIV/AIDS than they were a few years ago, they are still not adequately prepared to provide appropriate counselling. Other recommendations included better networking of existing services and more support groups and referral services.

It was felt that by bringing together professionals and interest groups from all regions of the province, the workshop would be an important first step in responding to these needs. Some participants suggested that following the workshop a regional action plan could be pilot tested and then evaluated for implementation province-wide.

The Workshop

OBJECTIVES

Goal 1. *To enhance HIV/AIDS counselling skills among participants, incorporating a sensitivity to the cultural needs in Nova Scotia*

Objective 1. To create awareness of existing regional resources and encourage participants to utilize them by providing informational materials and opportunities for personal interaction.

Objective 2. To increase knowledge of HIV/AIDS counselling issues by providing plenary sessions, small workshops, and discussion groups.

Objective 3. To address the diversity of cultural needs in Nova Scotia by inviting participation from the Native, Black, and Acadian communities.

Goal 2. *To encourage participants to take leadership in their region with regard to HIV/AIDS counselling*

Objective 4. To promote the establishment of a provincial HIV/AIDS counselling network by enabling interested individuals to come together.

Objective 5. To encourage the regionalization of HIV/AIDS counselling services by convening region-specific discussion groups for the purpose of processing information presented at the small workshops.

FORMAT

The workshop took place over a weekend, beginning on the evening of Friday, October 25, 1991, and closing after lunch on Sunday, October 27. There were three plenary sessions, and a total of 10 small-group workshops were held during three time slots (see Appendix 1 for a detailed agenda). The plenary sessions and

workshops included time for interaction and discussion. On Saturday afternoon participants came together in small groups to share perspectives and brainstorm future actions. Throughout, the emphasis was on creating a learning environment conducive to sharing experience, concerns, and feelings.

PARTICIPANTS

Of the 111 people who attended the workshop, 24 were provincial and national resource people selected to speak at the plenaries and workshops. The participants—all of whom had been invited to attend by the Advisory Committee—represented a regional and professional cross-section. They included doctors, nurses, social workers, clergy, teachers, guidance counsellors, activists, parents, and those who were themselves infected by HIV. The names and addresses of speakers and participants are listed in Appendixes 8 and 9, respectively.

Presentation Summaries

Following are highlights of the keynote address, plenary sessions, and small workshops.

Uncovering Counselling Skills as Buried Treasure

Keynote Address

Dr. Stephen Woo

Whether or not we feel personally at risk, as the HIV/AIDS epidemic progresses it is certain that we will all end up knowing someone who is. It is vital that we each learn about this disease and take this knowledge to our own region of the country. We need to examine our own resources, and we need to build long-term solutions. A better understanding of human psychology will make us more effective over the long haul. We will be able to overcome social and cultural biases, in ourselves and in others, that get in the way of caregiving. We will also be able to provide more effective education. As people in every walk of life begin talking to each other about the disease, we will begin to bring about change.

SOCIETAL ATTITUDES

Plenary Session

Yvette Perreault, Deborah Perry, Valerie Firth

Counsellors in the field of HIV/AIDS are bound to come into contact with socially stigmatized groups. To be effective, counsellors must first confront their own biases and be prepared to see the world through their clients' eyes. In this plenary session, three speakers highlighted issues related to homosexuality, prostitution, and drug use.

Yvette Perreault discussed homophobia and heterosexism, noting that eight out of every ten Canadians afflicted with AIDS are gay or bisexual. Counsellors need to overcome barriers created by homophobia by first going beyond fears and biases associated with "otherness" and then appreciating that otherness—realizing that gay and lesbian culture are both vastly different from heterosexual culture and worth celebrating in their own right (see Appendix 3 for a more extensive summary of Yvette's presentation).

Deborah Perry spoke on prostitution. In our society prostitutes are quickly labelled and afforded fewer rights than other groups. She urged counsellors to recognize the rights of prostitutes and to accept that they are knowledgeable about how to minimize personal and client risk for HIV infection.

Valerie Firth described the experience of being an injection drug user. She asked that counsellors make the effort to understand her world and that they be ready to offer genuine acceptance and support (see Appendix 4).

PERSONS INFECTED WITH/AFFECTED BY HIV
Plenary Session
Ron Dunphy, Kecia Larkin, Terry Martin, Marilyn Whitehead

In this session the presenters spoke from personal experience, to help participants "put a face on HIV/AIDS."

Ron Dunphy presented the perspective of the gay/lesbian community, which has been particularly hard hit by AIDS. He described the personal crisis of growing up in a society which teaches children that homosexuality is evil or sick, and then discovering that one's own sexual orientation is towards the same sex. The tendency within mainstream society to associate AIDS with the gay community has only exacerbated feelings of isolation and rejection. The gay community provides a mutually supportive and caring family for its members. Ron counted 29 close friends who had been infected with HIV: "Many have died, many are dying terrible deaths, and many are trying to live."

Kecia Larkin told her story of growing up in a native community off the coast of Vancouver Island. With her self-esteem undermined by the traumas of a dysfunctional family, she took refuge in the "familiarity" of street life and a series of abusive relationships. After being infected with HIV and reaching a crisis point of despair, she returned home and began a healing process that involved both herself and her family. She now speaks widely to native groups across the country, encouraging young people to talk openly about AIDS and the lifestyle choices available to them. She feels that young people need to have the right information; they also need to feel good enough about themselves to use that information.

Terry Martin described his experience of going through the steps of being tested for HIV: his fears, his reactions when he discovered he was positive, and his

concerns around the issue of confidentiality and acceptance/rejection by family, friends, and coworkers. He summarized the story of his struggle by saying, "I am living with HIV, not dying."

Marilyn Whitehead, the mother of a 19-year-old young man convicted with criminal negligence because he did not tell his girlfriend he was HIV positive, passionately implored the participants to join together in a united front to fight the disease. She also praised the existing support systems for families, which provide a refuge in a society that demonstrates widespread discrimination and nonconcern towards those infected with HIV/AIDS.

CROSS-CULTURAL ISSUES
Plenary Session
Lorne Izzard, Murdena Marshall, Madeleine Deveau

Nova Scotia's cultural diversity adds another dimension to the realm of counselling. The strong Black, Acadian, and Native communities in this province have special issues and needs to address, but they are not always able to provide their own counselling services.

In this session Lorne Izzard noted that Blacks have generally been left out of all AIDS education initiatives: culture-specific materials and representation on planning committees at all levels have been notably lacking. He concluded that this is a reflection of the deep-seated racism that still prevails in our country.

Madeleine Deveau profiled the Acadian community in Nova Scotia, which is an "invisible minority" characteristically bound by strong family ties and the Catholic faith. Acadians may tend to encounter HIV/AIDS with attitudes ranging from homophobia to a fierce survival instinct.

Murdena Marshall presented some of the relevant values, customs, and traditions of the Mi'Kmaq nation, which include a strong spirituality, belief in the Spirit as present in all of nature, seeing death as a natural part of the life cycle, specific rituals for mourning, and customs and beliefs affecting women.

STAGES IN HIV COUNSELLING
Workshops
Dr. Stephen Woo
Dr. Bernard Lapointe, Yvonne Lynch

A person who has been newly diagnosed with HIV infection does not have the same counselling needs as someone who has been living with HIV for a number of years and is experiencing medical complications. These two workshops identified stages of the disease and discussed how an individual's counselling needs change correspondingly. If an HIV antibody test is administered with consent, both pre- and post-test counselling are recommended. If test results are

seronegative, the objective of post-test counselling is to maintain this negative status. If seropositive, issues will depend on the phase of the disease: asymptomatic HIV, symptomatic HIV, or full-blown AIDS.

Stage	Strategy
1. Diagnosis: HIV positive – shock, inability to absorb much information	– simple information, some in writing, include contact names & phone numbers. – identify potential support people among friends and family, so they don't feel isolated and alone
2. Asymptomatic – stress associated with fall in T cells, loss of weight, etc. – stress of living with the disease & "waiting for something to happen"	– strategies for working with stress, possibly seeking alternative treatments
3. AIDS – fear of loss: job, home, sanity, family, friends, life, control	– dealing with fears associated with loss and death – learning to live with chronic disease and the side effects of medication

In Dr. Stephen Woo's workshop the issue of countertransference was also discussed—how to ensure that the caregiver's feelings and reactions assist in, rather than interfere with, the therapeutic process.

Note: To receive a copy of the report referred to in this workshop ("Highlights of Findings of the Mental Health Needs Assessment Study" by the HIV/AIDS and Mental Health Working Group), contact Dr. Stephen Woo directly, at the address listed in Appendix 8.

PRE- AND POST-TEST COUNSELLING

Workshops

Dr. Lynn Johnston, Johneen Pembroke

Jane Allen

As anti-retroviral therapy becomes more available, more people at risk are coming forward to be tested. These workshops provided guidelines for pre- and post-test counselling. In a pre-test session the counsellor assesses the degree of risk and discusses the pros and cons of testing. Once the individual chooses to go ahead and take the test, a post-test counselling session is arranged, regardless of whether the results are negative or positive. If the test is negative, the counsellor discusses the need for better precautions and also warns of the possibility of still being in the "window period." If the test is HIV positive, the counsellor must relate with the shock and emotional reaction that this news will bring. He or she then addresses the following issues over a period of several sessions: natural history of the infection, need for medical follow-up, support services available, treatment options, prevention of transmission, and contact tracing.

Jane Allen discussed some of the additional issues that come to play when working with street culture. For many of these people, HIV risk may take a lower priority than day-to-day survival issues, such as addiction, abuse, food, shelter, and childcare. Furthermore, because such groups as prostitutes and drug users have been marginalized by society, they tend to feel alienated from social services and health care systems. In these situations, outreach is a way of providing needed services and information, and the pre-test session is an especially valuable opportunity to communicate issues of safer sex and/or drug use. (See Appendix 5 for a more detailed summary of these workshops.)

PSYCHOSOCIAL ISSUES

Workshop

Leonard Duffenais, Nena M. Nera

The presenters brought two perspectives to this workshop: that of the person living with HIV (an infected hemophiliac) and that of the social worker/counsellor. Beyond the physical losses associated with HIV/AIDS, including sickness, dementia, and death, the person infected with HIV may also lose his or her job, lifestyle, goals for the future, friends, and self-esteem. Because the disease was originally thought to be limited to homosexual men, IV drug users, Haitians, and prostitutes, it is surrounded by the same social stigma that these groups collectively suffer. This prejudice leads to discrimination in housing, jobs, and medical treatment, and a general lack of social sympathy and support. All of these factors lead to feelings of fear and isolation, and produce "the psychosocial nightmare of AIDS."

The potential for healing goes beyond physical well-being or recovery and involves an emotional, mental, and spiritual reconciliation with oneself and one's situation. True healing begins when the person living with AIDS is able to take full responsibility for the disease and his or her health. This is not the same as accepting blame or guilt, but is a way of shedding the tendency to feel angry, victimized, and helpless. The challenge is to enter into the present moment and live each day to the fullest. This requires courage, openness, and honesty on the part of the individual as well as that of family and friends, even in times of despair and pain. It is the counsellor's role to assist with this healing process, by being available and accessible, and by being personally comfortable with the difficult issues facing the client.

BEREAVEMENT COUNSELLING

Workshop

Robert Allan, Sr. Cathleen Dunne

Issues of death and dying are central to HIV/AIDS counselling. Bereavement around AIDS is in many ways unique, in that it is an accelerated grieving process, often involving multiple losses (in one's own life as well as that of peers) and death at a young age. Social attitudes of self-righteousness and homophobia aggravate the pain of dying, and there is generally a lack of rituals for the lesbian/gay community, which is often not connected to a religious tradition. The counsellor helps the person to grieve by accepting his or her suffering without judgement or reservation.

ETHICAL/LEGAL ISSUES FOR COUNSELLORS

Workshop

Maureen Shebib, Brenda Richard

Confidentiality and discrimination are among the key legal and ethical issues that arise in the context of HIV/AIDS counselling.

Maureen Shebib reviewed the recently amended Nova Scotia Human Rights Act, focussing on sections relating to sexual orientation, physical and mental disability, exemptions, and common law doctrines militating against human rights protection for people with AIDS in the workplace. Other topics included medical and financial powers of attorney, wills, living wills, life insurance, custody of and access to children, and social welfare.

Brenda Richard examined the concept of ethics—the balancing of one good against another—and the codification of ethics in the NSASW Social Workers' Act and the Canadian Association of Social Workers Code of Ethics, which forbid discrimination with respect to sexual orientation. Other ethical issues specific to HIV/AIDS were also discussed.

WOMEN'S ISSUES
Workshop
Karan Whiteman, Kecia Larkin

Karan Whiteman, a single mother who is HIV positive, spoke of the concern for her young child's health and future. She also talked about the frustrations of dealing with the medical community and of her decision to turn to alternative forms of treatment, such as naturopathy, and to community groups for support. Kecia Larkin also endorsed alternative, more holistic, approaches to healing, including the spiritual need to get in touch with oneself.

YOUTH COUNSELLING
Workshop
Karen Pyra, Johneen Pembroke

Although there are still not many youths (aged 13-19) with AIDS, an increasing number of people in their twenties are being diagnosed HIV positive, and many of these contracted the virus during their teen years. Youth counselling is therefore primarily concerned with prevention and education. But what kind of education is most appropriate and most effective for young people today?

Karen Pyra suggested that heavy-handed warnings about AIDS at this impressionable age could lead to negative and fearful attitudes towards sex itself. The main focus of counselling should be on developing healthy attitudes, not on learning to associate sex with disease and death. Within that context AIDS can be presented as one of a number of preventable sexually transmitted diseases. Safer sex options should be thoroughly discussed, along with the means for implementing those options. Young people should be helped to develop the skills to say no to unwanted sexual behaviours, to use condoms correctly, and to negotiate with a partner about safer sex practices. Counsellors need to feel comfortable discussing sex and AIDS, and they need to be prepared to view this aspect of young people's education as a long-term process.

Johneen Pembroke underscored the need to respect adolescents' experience: counsellors must be ready to approach young people on their own level, with their own language, and with a sensitivity for their values, concerns, and way of thinking (see Appendix 6 for a more detailed summary of Johneen's presentation).

Evaluation

THE QUESTIONNAIRE

Thirty-two participants completed the evaluation questionnaire at the end of the workshop. This represents a survey of 29% of the total number of participants (including speakers) and 37% of the non-presenting participants. Below are the results.

1. *Did the workshop meet your expectations?*

yes	91%
no	6%
mostly	3%

2. *Overall, how would you rate the workshop?*

Rating (5=high)	Societal Attitudes	Persons Infected with/Affected by HIV	Cross-cultural Issues
5	80%	78%	60%
4	20%	19%	23%
3	0	3%	17%
2	0	0	0
1	0	0	0

excellent	88%
good	12%
fair	0%
poor	0%

3. *On a scale of 1-5 (5 being the highest rating) how would you rate the plenary sessions?*

4. *Will you apply or share what you have learned after the workshop?*

yes	100%
no	0

5. *Do you have any further comments?*

This question elicited a wide range of responses, which were almost universally positive. Participants expressed particular appreciation for the plenary sessions.

MEETING THE WORKSHOP OBJECTIVES

Following is an analysis of the five workshop objectives, as originally established by the Advisory Committee.

Objective 1. To create awareness of existing regional resources and encourage participants to utilize them by providing informational materials and opportunities for personal interaction

One of the most valuable outcomes of the workshop was that people from interest groups across the province were able to meet each other and share information. This created an important foundation for future networking. The workshop format did not specifically provide a forum for exchange at a regional level; however the participants left the workshop with a list of each other's names, affiliations, and addresses.

Objective 2. To increase knowledge of HIV/AIDS counselling issues by providing plenary sessions, small workshops, and discussion groups

The plenary sessions and workshops provided orientation and information related to a broad range of counselling issues. Of the participants who completed the questionnaire, 91% said the workshop as a whole had met their expectations, and 100% said they planned to apply or share what they had learned.

Objective 3. To address the diversity of cultural needs in Nova Scotia by inviting participation from the Native, Black, and Acadian communities

The advisory committee invited representatives from these cultural communities to attend the workshop, and the plenary session entitled "Cross-Cultural Issues" introduced all the participants to some of the cultural issues relating to HIV/AIDS counselling.

Objective 4. To promote the establishment of a provincial HIV/AIDS counselling network by enabling interested individuals to come together

Participants almost unanimously expressed a desire to maintain contacts that had been made at the workshop. In the Saturday discussion groups, strategies were proposed for developing alliances among counsellors and multidisciplinary cooperation.

Objective 5. To encourage the regionalization of HIV/AIDS counselling services by convening region-specific discussion groups for the purpose of processing information presented at the small workshops

It was originally planned that the Saturday discussion groups would be divided according to region. However, because this would have left some groups with a very small number of people, it was decided instead to divide the participants randomly.

THEMES AND IMPRESSIONS

Participants were asked to write their feedback on comment sheets supplied at the end of individual sessions. This information, along with the answers to the last question on the questionnaire, was an important component of the workshop evaluation. The most common one-word responses to the individual sessions were "informative," "inspiring," "moving," "powerful," "excellent," and "practical." More detailed responses tended to cluster around a number of key themes.

Participants expressed appreciation for the overall tone of the workshop, which tended to be personal and experiential, rather than academic. One participant noted, "Nothing is more eloquent or powerful than hearing individuals speak from their own experience." And another: "[The workshop] generated warm relationships and a safe place to risk in sharing." This tone also placed a demand on the participants, some of whom found the emotional rawness and intensity exhausting. Everyone seemed to agree, however, that this kind of approach was needed if counsellors were to overcome personal barriers of fear and prejudice. There was an invitation to discuss and share, as well as to listen. A couple of participants suggested that this dimension could have been taken one step further, with opportunities for role playing.

This experiential tone was in many ways set by the presenters, most of whom were able to speak personally of the suffering caused by the disease, either as counsellors or as those infected with HIV. They were able to offer practical advice, and this too was greatly appreciated by the participants: "It was refreshing to have a grassroots, practical, inquiring session rather than the didactic material that predominates in the medical community." "The choice of speakers could not be topped...." "The most important aspect of this conference was the personalizing of HIV/AIDS."

Another strength of the workshop was the exposure to a number of different cultural and social groups, each with its own concerns regarding HIV/AIDS counselling. Participants were encouraged to confront and explore their own preconceptions and prejudices about gays/lesbians, prostitutes, drug users, and minority cultural groups, and to try to understand what it is like in those sometimes unfamiliar shoes. There were times when participants perceived this challenge to have gone too far—to have crossed over into a self-righteousness. One person commented, "I was appalled to see the straight bashing," and another complained of the "rather inappropriate maligning of individuals, agencies, and heterosexuals...." However, the coming together of these groups was in itself an important first step in developing a united front against AIDS in this province, and the workshop provided an opportunity to affirm this common goal: " This disease needs all of us working together in a partnership of friendship. Together we are stronger...." "Keep the dialogue happening and the partnerships will come if people respect each other's realities."

This leads to another theme, which is the realization that this workshop is only the beginning of a much larger process. One participant admitted, "It didn't meet my probably naive expectation that I would come out of it a skilled counsellor.... We need to go much further in terms of developing expertise for concrete preventive and counselling skills." Everyone agreed that there is much yet to be done in the way of communicating, training, networking, and providing services and facilities. Nevertheless, the workshop was a strong and important gesture in this direction: "I have never, in 25 years of conferences, heard so many first-class presentations. Merci!" "The government got excellent value for the money it invested."

Where Do We Go from Here?

First on the list of the workshop's "Guiding Principles" was the affirmation that "the initiative is a process, not an event." The workshop was an important contribution to the ongoing education needs of everyone working in the HIV/AIDS field in Nova Scotia. It strengthened the participants' commitment to continue developing counselling skills and to continue building a provincial network of professionals, caregivers, and those who need care.

During the discussion groups, participants were asked to brainstorm what should happen next—how they could personally carry what they learned at the workshop back to their respective regions and communities and what initiatives at the government level would most effectively carry the momentum of the HIV/AIDS initiative forward. Following is a list of recommendations in both categories.

TAKING IT HOME

- Publicize the weekend: talk about what happened and what was learned.
- Use the media to create community awareness (e.g., radio spots).
- Set up local networks by contacting local agencies, clergy, and helping professions.
- Connect rural areas to distant resources and metro agencies.
- Hold local counselling workshops to improve existing skills.
- Provide training for volunteer counsellors.
- Let physicians know about community-based groups.

CARRYING THE INITIATIVE FORWARD

- Produce an inventory of local resources to facilitate referrals.
- Present a workshop on pre- and post-test counselling for physicians.
- Develop and maintain communication channels among professions and between professionals and clients.
- Establish an AIDS clinic with satellite support organizations.
- Delineate a formal list of ethical and legal considerations related to HIV/AIDS counselling (i.e., standardized provincial guidelines).
- Continue networking across the province.
- Establish and maintain local counselling networks.
- Develop services specific to HIV counselling with an emphasis on rural areas.
- Strengthen existing support systems and develop new ones.
- Encourage a closer liaison between metro area groups and groups in rural areas to help develop and strengthen rural groups.
- Work towards ending the stigma of living with HIV.

Closing Remarks

by Nena M. Nera
Social Services Advisor, National Aids Strategy
Health and Welfare Canada

I believe that something special always happens when a group of people such as this comes together—people who are willing to share their feelings and concerns, and take risks. But in a few moments we will be saying goodbye to each other and some of us may not meet again. In this vein, I would like to make two suggestions before I share my personal observations and reflections from the past two days.

The first suggestion is for each of us to reconnect with at least two individuals next week, another two the following week, and then another two the third week, until we have reconnected with all the individuals we met here this weekend. This will strengthen and solidify the extensive networking that has happened here.

My second suggestion is that during the next two to three weeks we all accept Dr. Stephen Woo's challenge to share our experience and the knowledge we gained with 5 other persons. With the 111 individuals registered here, we will be reaching

555 people, and if each of these 555 reaches 5 others, within six weeks we will have out-reached to 2775 individuals. That is what we call the multiplier effect. If we want it to work, it has to be done purposefully—that is, it has to be a disciplined follow-up. Shall we give it a try?

And now, as this workshop comes to a close, let me share some of my own reflections about HIV/AIDS counselling. We have had a great deal of discussion and exchange, stimulated by powerful plenary and panel speakers. Following are some observations and projections resulting from this discussion.

I foresee that in the second decade of the pandemic we will continue to celebrate with the gays and lesbians, as we have done in the first decade, but we will also need to celebrate with HIV-infected women, children and their families, adolescents, natives, and others. We have to be sincere when we say that HIV is everyone's concern and that HIV/AIDS does not discriminate.

In the second decade, I also see us continuing to meet the challenges of homophobia, but we will also be challenged to minimize heterophobia.

We will continue to journey together and bear witness to the number of "heroes" and "heroines" of this pandemic. But let us take time to acknowledge the hero in ourselves and to remember those who have died or are too sick to be here with us this weekend.

I hope that the experience of this weekend has taken us beyond ourselves and given us the opportunity to come into contact with our own Self—I mean the inner core of one's self, which is perhaps where the "buried treasure" lies. We know that each one of us has the inner strength to transform a dead end into a path, a wall into an opening; with this comes the feeling of being connected to all things. To come into contact with this inner strength is to uncover our buried treasure.

In conclusion, HIV counselling is part of the healing process, and healing is available for all of us who go through the AIDS process—whether as counsellor or as the individual being counselled. As we have ourselves discovered, we all have a lot of healing to do. Healing is found in experiencing the true meaning of one's personal power, in loving even through despair, and in trusting in a Higher Power, or in the life process itself, when everything else seems to have been stripped away. Healing means to confirm one's value, one's essence, to stand tall, to possess the sudden burning desire to love, to be generous, to go beyond one's self.

And now, I would like you all to join me in applauding the Advisory Committee members, who were responsible for making this weekend a great success. They have been hard working, and you have seen and experienced the result of their work. Working together, we have had some growing pains, just like any other

committee, but we also have had a lot of fun. Thank you especially to Theresa Marie Underhill, who has worked especially hard as my provincial contact person. Thank you also to Paula Veinot, for the excellent job she has done in coordinating the work of the committee. My own personal thanks go to all the committee members.

Needless to say, the success of this weekend has also been due to you, the participants. My sincere thank you for your attendance, interest, patience and understanding, as well as your willingness to learn, to share, to take risks, to challenge and be challenged.

I would like to leave you with a quote by one of my favourite novelists, Thornton Wilder: "There is a land of the living and a land of the dead; and the bridge is love—the only survival, the only meaning."

Appendix 1

WORKSHOP AGENDA

25-27 October 1991
Oak Island Inn
Western Shore, Nova Scotia

Friday

7:00 pm **Opening Remarks**
Theresa Marie Underhill (Conference Chairperson), Director, Health Promotion, N.S. Dept. of Health

Cathy MacNutt, Deputy Minister, N.S. Dept. of Health

Nena Nera, Social Services Advisor, Federal Centre for AIDS, Health and Welfare Canada

Keynote Address
"Uncovering Counselling Skills as Buried Treasure." *Dr. Stephen Woo*

Saturday

9:00 am **Plenary:** Societal Attitudes
Yvette Perreault, Deborah Perry, Valerie Firth

10:15 am **Workshops**
Stages in HIV Counselling. *Dr. Stephen Woo*
Pre- & Post-Test Counselling. *Dr. Lynn Johnston, Johneen Pembroke*

12:00 pm Lunch

1:30 pm **Plenary:** Persons Infected with/Affected by HIV
Ron Dunphy, Kecia Larkin, Terry Martin, Marilyn Whitehead

3:00 pm Break

3:15 pm **Workshops**
Psychosocial Issues. *Leonard Duffenais, Nena Nera*
Bereavement Counselling. *Sr. Cathleen Dunne, Robert Allan*
Ethical/Legal Issues for Counsellors. *Maureen Shebib, Brenda Richard*

4:30 pm **Discussion Groups**

7:00 pm Dinner & Entertainment: Trinity Theatre Group

Sunday

8:30 am Non-denominational Sunday Service

9:30 am **Workshops**

Stages in HIV Counselling. *Dr. Bernard Lapointe*
Pre- & Post-Test Counselling. *Jane Allen*
Women's Issues. *Kecia Larkin, Karan Whiteman*
Youth Counselling. *Karen Pyra, Johneen Pembroke*

11:00 am Break

11:15 am **Plenary:** Cross-Cultural Issues
Lorne Izzard, Murdena Marshall, Madeleine Deveau

12:30 pm Lunch

Closing Remarks
Nena Nera, Social Services Advisor, Federal Centre for AIDS, Health & Welfare Canada

Appendix 2

NEEDS ASSESSMENT INTERVIEW QUESTIONS

1. What is your definition of "counselling"? That is, what does "counselling" mean to you?
2. Who do you go to for counselling? Where do you go?
3. Are there HIV/AIDS counselling services and people to provide these services in your area?
4. What are these services and how available are they?
5. Are you satisfied with the services presently available?
6. What does this community need, either now or in the near future, with respect to HIV/AIDS counselling?
7. Whichof these needs is/are most important?
8. What could be done to help provide these needs?
9. Are there any other problems with the HIV/AIDS counselling services presently available in the area?
10. What can be done about these problems?
11. In your opinion, do individuals in your professions know enough about HIV/AIDS and related issues to help individuals who ask for counselling?
12. In your community, do people working in HIV/AIDS related jobs (i.e., counsellors, physicians, etc.) get together to share information or talk about issues?
13. What can be done to get professionals to work together more?
14. In this community do people know where to get HIV antibody testing?
15. Are people getting HIV antibody testing, if they want it? Why or why not?
16. Do individuals who go for HIV antibody testing believe that their right for privacy and confidentiality is being respected?
17. In this area, how do people feel about homosexuality, injection drug use, and prostitution?
18. Define homophobia. Does homophobia exist in you community? Is it common?
19. How much does the community know about HIV/AIDS, in general, and

counselling and testing, specifically?

20. In your opinion, how comfortable is this community with HIV/AIDS—with people living with HIV/AIDS and others who are affected?
21. Should the workshop provide information only, or should it go one step further by giving people the chance to develop plans to improve HIV/AIDS counselling in their own regions? (What does the group feel the objectives of the HIV/AIDS Counselling Workshop should be?)
22. What experience would you like to gain by the end of the workshop?
23. Summarize themes and issues, features of effective HIV/AIDS counselling workshops, suggestion for speakers.

Appendix 3

IMPACT OF HOMOPHOBIA AND HETEROSEXISM ON HIV/AIDS COUNSELLING

Based on a presentation by Yvette Perreault

Homophobia is defined as a fear of lesbianism/homosexuality. Heterosexism is the belief that heterosexuality is the best form of sexuality, and that heterosexual relationships are better than lesbian or gay relationships. These feelings and attitudes are deeply engrained in our society and haunt HIV/AIDS counselling issues at every step, even when the client is heterosexual.

Historically, homosexuality has been viewed as a sin, a sickness, or even a crime to be punished. In 1973 the American Psychological Association removed homosexuality from its list of psychological disorders, and *sanctioned* prejudice came to an end in our society. However, the gay community was only beginning to develop self-acceptance and to explore how to integrate into society in a positive way when the AIDS epidemic hit in 1981.

AIDS forced a collision of worlds: gays and lesbians needed help from the same counselling services and institutions that had for so long discriminated against them. The struggle for the gay community has been to resist seeing themselves as "victims" and "service recipients" but instead as a people engaged in a struggle for their own liberation who need effective partners and allies.

The Nova Scotia Human Rights Act now forbids discrimination based on sexual orientation; however, counsellors have little guidance for how to think about or work with gay and lesbian clients. Most heterosexual counsellors believe that avoiding traditional attitudes of fear and loathing is enough, while continuing to assume that being gay is less than normal, or at least less preferable. Therapists have not yet really considered what it means to work with theories and values that are all based on a heterosexist model of society. Similarly, before the wave of feminist and anti-racist critique, the mental health profession had not examined its disempowering and culturally inappropriate assumptions and messages toward women and blacks.

With the best intentions, counsellors may still be echoing negative messages to gay and lesbian clients; this only adds to baggage of secrecy, shame, and fear of disclosure and blocks the client's need to integrate and explore. Heterosexual counsellors need to go far beyond mere tolerance and acceptance and develop positive attitudes of support, admiration, appreciation, and nurturance. They need to be willing to combat homophobia in themselves and others, to be strong advocates in safeguarding the rights of gays and lesbians, and to feel genuine

appreciation and delight towards gay and lesbian culture.

The best way to accomplish these goals is through experiential exercises:

1. Ask yourself the following questions: Do I believe that someone who is lesbian, gay, or bisexual can be happy and fulfilled? Am I able to accept and validate my clients' anger at homophobia and heterosexism, in others and in myself? Am I open to questions about my feelings and attitudes towards lesbians and gays? Am I aware of the strain of leading a secret life (being in the closet)? Can I support my client's "coming out"? Do I know or would I find out about community resource groups and books that would be helpful to my non-heterosexual clients? Do I believe it is possible to feel a sense of self-acceptance and pride about being lesbian, bisexual, or gay?
2. Conspicuously carry a copy of the local gay/lesbian newspaper *or* wear a gay rights button for one full day and note your own feelings (vulnerable/ self-conscious/ ashamed/ fearful/ etc.).
3. Hold hands with a friend of the same sex downtown.
4. Tell people you are exploring same-sex attractions.
5. Solidly confront a "queer" joke.
6. March in a gay/lesbian protest.
7. Write a letter to the editor advocating equal benefits for same-sex couples.
8. Read lesbian/gay erotica.
9. Ask gay/lesbian coworkers and/or members of your community what support and nurturance they need from you to be fully and wonderfully themselves.

For those of us who are gay or lesbian counsellors, it is important that we not remain isolated, and that we deal with our personal fear and shame. We need to articulate our needs and develop our own role models. If we are not absolutely proud, even in the face of lies, how can we expect a society that is already uncomfortable around issues of sexuality in general to offer us more than pity, fear, and the intention to "fix" us. ***We must celebrate ourselves.***

In conclusion, the Afro-American poet Pat Parker once gave this advice to potential cross-cultural allies: "For the white person who wants to be my friend: first you must forget that I am black; second you must ***never*** ever forget that I am Black." Similarly, to the heterosexual counsellor who wants to be a supportive and effective partner in this AIDS war: first you must see our completeness and humanity, not our "otherness"; second, until this society is radically transformed, you must ***never*** ever forget that our reality, as gays and lesbians, is fundamentally different from your day-to-day experience.

Appendix 4

"I AM AN IV DRUG USER"

by Valerie Firth

My name is Valerie. I am an IV drug user. I am as addicted to needles as I am to drugs. When I wake up with my arms stiff and sore from IV drug use, I feel strong. Around some people I wear my track marks like badges of honor. I think of my veins as valuable assets, using some while nursing others back to health. I have small veins that wear out very quickly so I have to treat them very carefully. Upon meeting you, one of the first things I will notice about you is your veins. I search my whole body for veins that can be used. I use the veins on my arms, on my wrists, on my ankles, on my legs, on my breasts. Sometimes when shooting I miss the vein or rupture it. Then a large red lump will appear and the area may swell. Sometimes a miss may abscess. I also bruise from shooting. Sometimes I shoot so many times in the same place that I leave open sores. I don't care. I still keep shooting. Sometimes I will find a vein and then lose it and I have already flagged so I have blood in my syringe. If I am not real fast at finding another vein the blood will congeal in the needle and I will lose my hit. The higher you are the more difficult it is to find a vein. Everything feels like a vein when you are high. I can sometimes spend half an hour or even an hour looking for a vein to hit. But I am determined. I won't give up my hit. When I go a few days without drugs my veins begin to itch. I know they are healing.

When it comes to needles, my main concern is not cleanliness but the sharpness of the point. My best high depends upon a good, sharp point and a direct hit. The sharpest point is a new, clean needle. Dull needles tend to push veins aside rather than puncture them, especially if veins are already scarred.

I am concerned with cleanliness, though, and I do try. When I have a new bag of fits, I have the best of intentions. I always start out watching very carefully to see who is using what fit and placing it where, and where I am setting mine down. But after awhile I get confused and desperate and pick up any needle that is available. I'm no longer sure if it is mine or if it belongs to someone else. I know in my heart that if worse came to worse I would pick a fit out of the gutter and use it. After all, haven't I used toilet bowl water to mix up a hit? Keeping track of clean needles is especially hard when I am using cocaine—my drug of choice—because I use so much so fast and it quickly becomes very confusing as to who belongs to what fit.

I know other people who are addicted and like to believe they are less addicted than me because they don't use needles. As if addiction comes in varying degrees. I know they shake their heads and say I'm sick. I guess we all have to find someone to feel better than.

I know what the pharmacist thinks about me when I ask him for needles. I see the way he looks at me. I see the way you are looking at me.

I'm not afraid of death. Death is the ultimate high. At least that is what I say, but when I do take too much of the drug and go under I always fight real hard to come back. I know I am afraid of brain damage, of being disabled.

People say I should go to a doctor. I already know I have hepatitis B. They say I should have an AIDS test, but I'm not comfortable with doctors. I don't know how to talk to them unless I am conning them for a drug I want. Besides, I can't go uptown for a blood test. I can't go straight cause I'm a mess straight, and I certainly can't go high. I'm a mess high. I hate blood tests. They make me want to use. I sit there waiting for the rush that doesn't come.

I guess what I want from a counsellor is some acceptance, some understanding of what it is really like for me. You can't just hand me a few fits, a pamphlet on Javex cleaning, and a lecture. You have to talk to me for real, know I try, and encourage me to try more. Hold my hand. Go to a doctor with me. Bring a doctor to the street. Why can't blood be taken in the street? After all, it's not only me I may be hurting, but if I don't care about myself how can I be concerned for someone else's health and safety? But by taking care of me you may save so many others.

Appendix 5

PRE- & POST-TEST COUNSELLING

A summary of presentations by Dr. Lynn Johnston, Jobneen Pembroke, and Jane Allen

The process of HIV testing includes the important components of pre- and post-test counselling. During the pre-test session the counsellor should arrange for the individual to return in person, so that the implications of either a positive or a negative test result can be discussed. In practice, however, people often do not return to a nonmedical agency (e.g., an AIDS organization) for post-test counselling. Taking this into account, the time spent in pre-test counselling is especially valuable, and a counsellor must often impart information that would ideally be included in a post-test counselling session.

In determining whether a client should undergo HIV testing, the counsellor determines why the individual has come forward—i.e., which risk behaviours are involved. This will help to better counsel the client as to the likelihood of a positive test and will also influence the interpretation of the test results. As human beings we do not want to see others in pain, and we may feel the tendency to downplay the seriousness of high-risk behaviours. However, it is the responsibility of the counsellor to be honest with the client in discussing the level of risk involved, without creating undo panic. Each counsellor must find his or her own way of accomplishing this.

Before being tested, the client should understand the significance of both positive and negative test results. He or she should know what type of information the clinic/physician sends to the Provincial Department of Health, and what type of testing we have in Nova Scotia. The counsellor would also discuss the pros and cons of knowing one's HIV status. For some individuals, knowing brings its own "peace of mind." Finding out that one is not HIV infected is an opportunity to commit to maintaining and protecting one's health status. There is also the relief of knowing that one is not responsible for passing on the virus to past and present sexual partners or to the persons with whom one has shared IV needles. A positive test result allows the client to take advantage of any early medical interventions that are currently available. Such individuals are motivated to protect their partners from infection, and they are also able to make informed choices about their own health care and future plans.

There are, however, some arguments against being tested for HIV. Many individuals question their ability to cope with the knowledge of being HIV positive. There is a perceived/real concern about the loss of control over one's life and body. Some individuals feel that knowing their HIV status would result in a

loss of autonomy regarding lifestyle choices and medical interventions. Perhaps the biggest argument against testing is the fear of rejection by people who comprise one's support system. There is also a feeling of having to sacrifice one's privacy and confidentiality, and a practical concern with regard to the effect on one's employment status and ability to purchase or increase life and health insurance.

It is the role of the counsellor to explore all of these pros and cons with an individual who has come forward, and to encourage him or her to make the decision about testing that is best for them. A counsellor must therefore empower the client to make an informed choice.

The final component of a pre-test session is telling the client where to go for an HIV test (family doctor, clinics, etc.). Should the individual decide to go for a test, he or she should be encouraged to have someone go along for support or, at the very least, make sure someone is available to talk to afterwards. The counsellor's working knowledge of community support systems is important at this point.

The client should always be encouraged to follow through with post-test counselling, whether the test result is positive or negative. In the event of a positive test result, counselling will require several sessions as there is a great deal of information to be assimilated. From a medical perspective, information needing to be covered includes: natural history of the infection, need for medical follow-up, treatment options, contact tracing, issues unique to women, and the prevention of transmission to sexual and/or needle-sharing partners. It is also important to talk about the individual's feelings and fears. Chances are, if someone says they are "okay," they aren't. Validate the person's reaction, and reassure them that it is normal to experience a range of emotions. Often it is the role of the counsellor to provide emotional support. This may involve a referral for further support and/or counselling.

It may seem that there is no need for post-test counselling if the test result in negative. This, however, is not true. Such individuals should be alerted to the possibility of being in the window period and the possible need for follow-up testing. They should also be reminded that the result does not mean protection from future infections.

Finally, we must remember that there are no high-risk groups, only high-risk behaviours. As counsellors, we cannot make assumptions about an individual's HIV status based upon his or her social group: prostitutes, gay men, IV drug users, and so on. The challenge is to encourage each individual to think about issues of lifestyle and sexuality as they relate to personal health and safety.

Appendix 6

YOUTH COUNSELLING

by Jobneen Pembroke

Adolescents in today's society are bombarded daily with issues that most adults never had to face so early in life: addiction; physical, emotional, and sexual abuse; pregnancy and parenting; homelessness; and now, AIDS. Many adults did not have to compound the sexual confusion of their adolescence with fear of a sexually transmitted disease that could kill them. I believe that today's youth deserve the respect of adults, and it is with this respect that the subject of sexuality and HIV/AIDS should be approached.

It is important that an adult who is discussing issues around sexuality be able to relate to young people on their own level. We often expect adolescents, who may be physically full grown, to think and act like adults. This is unrealistic. Adolescents do not think like adults, nor do they always make responsible decisions about their lives.

Many young people, for various reasons, have not been taught the "medical" terminology for body parts and sexual acts. They use the language of their peers: slang. If you are using the term "vaginal intercourse" with a young woman who uses the word "fucking" to describe the same act, it is as if you are speaking two different languages. She may not understand the information you are trying to impart, and she may feel stupid because she doesn't know the "correct" term. At the least, she will feel that you are on two different wavelengths. This will be a barrier to your communication and to the impact of the information you are trying to impart.

It is important to find out what an adolescent actually knows about sex, sexuality, and HIV/AIDS. In the presence of an adult, young people will be reluctant to admit ignorance about these issues. Or they may have absorbed a great deal of misleading information from peers and the media. Do not assume anything about their knowledge base. It is better to err on the side of caution and start with the basics.

In my experience, adolescents are ***extremely*** perceptive—far more perceptive than adults. If you are at all uncomfortable discussing issues involving healthy sexuality, sex, and HIV...they ***will*** know. If you are uncomfortable using the language they are using...they ***will*** know. If you are patronizing and do not view them and their set of experiences with respect...they ***will*** know. If you disapprove of their being sexually active...they ***will*** know. As an adult working with youth, it is important that you explore your values around adolescent sexuality and be able to provide

them with information in a nonjudgemental manner. If you are unable to do this, be honest with yourself, and them, and make a referral to someone who will be able to work with this issue. Empowering young people to make healthy lifestyle choices is an issue that is too important to sacrifice through your own discomfort.

Appendix 7

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